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The Linacre Quarterly

Volume 55 | Number 4 Article 9

November 1988

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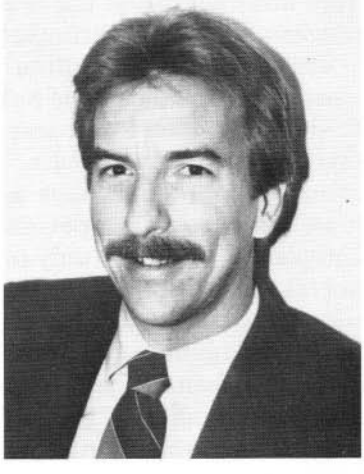
Recommended Citation

Karl, George T. (1988) "Death, Disability and Medicine: A Need for Public Education," *The Linacre Quarterly*: Vol. 55: No. 4, Article 9.
Available at: http://epublications.marquette.edu/lnq/vol55/iss4/9

Death, Disability and Medicine: A Need for Public Education

Rev. George T. Karl



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In recent years, tremendous advancements have been made in sustaining bodily functions for a person who is no longer able to do so for himself/herself. Respirators, ventilators and pacemakers have added to the marvels of powerful medication which can sustain a body almost indefinitely. In the midst of this advancement, society as a whole has little comprehension of the ramifications of such technology and even less understanding of its potential effect on one's personal life.

The average person does not entertain the possibility of one day being placed in a position of having to say "Do not resuscitate", "Do resuscitate", "Do not put him/her on a respirator" or "Do put him/her on a respirator". Unfortunately, many people will find themselves in the position of having to decide, and when the time comes, they will be both intellectually and emotionally unprepared.

The problem confronting the health care professional is the lack of public education regarding medical issues. The public's ignorance of the realities of health care leads to an unrealistic expectation of medicine as a whole. This disparity between the health care professional and the general

public involves medical expectations and ethical awareness. Health care professionals encounter ethical decisions daily, and as a whole, they are making great strides in their understanding of medical ethics. However, health care professionals comprise only one of the many parts in the scenario of life and death decisions. In most states, legislation dictates a significant role to the family and specifically to the next-of-kin in the decisions affecting the prolongation of life. It is this player — the average person on the street — who is ignorant of the issues he/she may face. Such ignorance on the part of the general public and, at times, an arrogant paternalism on the part of the health care professional, further confuse the basic issues of life and death. It is difficult enough for any person to make a decision involving a loved one's life and death, much less someone who does not understand the ramifications of ventilating or not ventilating, resuscitating or not resuscitating.

There is no easy solution to this dilemma. The only way to help the situation is to educate the public concerning medical issues. This involves raising the public awareness of the reality of disease and trauma, of the limitations of health care, and of suffering and death. Such public education is a moral issue which cannot be ignored. The general public must learn that when persons become sick or injured, some will recover completely, some will only recover part of their former self and some will not recover at all. To ignore the need for such public education is to render support to the general belief that medicine and medical technique, when properly administered, can cure and fix anything — a belief which leads to litigation when the physician and/or surgeon fails to cure or to mend the sick and the injured. In essence, there is, on every street corner, a well-meaning person declaring lay medical and ethical opinions from his or her limited personal experience. Such persons not only over-simplify health care, but also claim authority on issues about which they have little knowledge.

Trust of the Past

In former times, patients trusted the decisions and opinions of their physician, a person who was both educated in health care and responsive to the patients' needs. Today, in times of litigation, living wills, resuscitation and powerful drugs, the public is asserting its own will. Generally, persons expect signs of a miraculous recovery. These expectations are supported by the belief that "to heal" means to make them like they were. A trauma victim expects to be able to recover all of his/her former function and if he/she does not, it is the fault of the medical care. The general public wants to avoid the issues of death and permanent disability, events which are realities in our world, yet events of which the public remains willfully ignorant.

Where does one begin with this public education? First, it must begin in day-to-day medical care. The public must be helped to see that we will all

die and secondly, many of us will be involved in decisions affecting the death of the ones we love.

Education of the public is a difficult task and ideally would be done prior to a loved one's illness or injury; however, it cannot be side-stepped in favor of a more opportune time. It is the responsibility of the medical center to help families process the information they are given. They must receive adequate information about the patient's condition and be helped to understand its meaning in order to make an informed decision. The operative word is "adequate", since too much information will cloud the issue and confuse the family members. For example, it would be inappropriate for the medical staff to explain the situation in such a manner as to confuse the family. Medical jargon must be translated into lay terms. Likewise, it would be inappropriate to mislead the family into a false sense of hope by not speaking about the true condition and prognosis of the patient.

Problems with Injury, Illness

Obviously there are major problems with the education occurring at the time of injury or illness, though these problems do not override the need for the education. One such problem is the potential value the next-of-kin places upon the physician and nurses. Many families project an omniscience or "all knowing" capability onto the medical staff. These families hang onto every word and every inflection of the speaker's voice in an attempt to decipher his/her opinion. They want to be told what to do and, in the process, be removed from the responsibility of having to decide for themselves. In such a situation, the health care professional may inadvertently be manipulated into suggesting a decision to the family.

This problem is also influenced by the health care professionals' needs. Being human, health care professionals are influenced by their own beliefs and cultural upbringing. Whether they are conscious of the act or not, they may influence families. For instance, a health care professional who places a high value on living will communicate this and may influence the familiy into giving permission for "heroic" efforts. In such a situation, the health care professional may present a "rosy" picture and, in the process, elicit a desired response. Such a professional acts out a philosophy of life which places emphasis upon the *quantity* of life, believing any form of life is valuable. On the other hand, some health care professionals place a high value on the *quality* of life, believing there are worse things than death. These professionals want to avoid extending the patient's "suffering".

The problem with each of these positions is that they ignore the patient's own view of life. The medical staff and/or family have, in essence, taken over the patient's life as they attempt to make decisions out of their own personal belief system. They should be attempting to make the decision according to what they think the patient would want.

In summary, the first ethical problem is that of power and influence. Who decides, who influences whom, and who respects the patient's wish?

An Additional Ethical Problem

Another ethical problem arises in communication. It is a given fact that the health care professional and the family often speak a different language. For example, during a cardiac or pulmonary arrest a physician may talk to the family concerning continuing the resuscitation effort. This is usually done by asking "What do you want me to do?" The general response is "Do all you can." What seems to be a straightforward conversation is actually a failure to communicate due to assumed meaning. The physician is interpreting the statement, "Do all you can" to mean "Continue the code." The family is interpreting it to mean, "Do all you can, so that mother can come back home as she was." The two interpretations are quite different — so different that there needs to be some clarification of the true expectations on the part of both parties.

The health care professional needs to state what he/she foresees as a prognosis for a patient and what is involved in continuing heroic action. If, in the opinion of the physician, the person has little or no chance of surviving, then this needs to be declared so that the family can make an informed decision. Furthermore, the family needs to talk to the physician and express its true expectations. Obviously this requires a clearly developed relationship between the physician and the family and it requires that time be spent with the family and patient.

A final ethical problem concerns who is in control of the patient's life. All too frequently, hospitals face the issue in which both the health care professional and family members exceed their rights in interfering with the physician-patient relationship. For example, there is a tendency for children of elderly patients to overrule the physician-patient relationship and to place their desires against that of the patient. Does the family have the right to take over the medical decisions of a patient who is of sound mind, but is diagnosed as having a terminal illness? Does the family have the right to pre-empt the physician-patient relationship simply because the patient is old? Conversely, does the health care professional have the right to decide whether the patient is to be told medical findings, especially when it is the patient who came to the doctor for medical help? At all times, the pre-eminent relationship should be between the physician and the patient and information must flow freely between the physician and patient.

Lying Destroys Trust

To lie to the patient or to withhold requested information is to destroy the trust necessary in a physician-patient relationship and to interfere with the patient's ability to test reality. To avoid answering the patient only heightens the patient's anxiety and, in the process, signals to the patient that there is something wrong. Any person, including an ill patient, can

sense the change which occurs in a relationship when he/she is suddenly placed outside of the information loop. Likewise, at some level, every patient knows when he/she is being lied to, can sense misinformation and is clearly aware of those who avoid the question.

In summary, there is a lot of work to be done. Educating the general public about health care will begin with the health care provider. The more the patient and family are involved in medical care, the more they will learn about the reality of medicine and health care. Likewise, if the health care provider avoids doing the education, then the learning will come from the hallways, waiting rooms and street corners. This pseudo-education will often be inaccurate and misleading. Public education in the area of health care will, unfortunately, happen at the most inappropriate and inconvenient time — during the death of a loved one. It still must occur and the effectiveness of the education will depend upon the honesty and openness of the health care professionals.
